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# **“THE QUEST NARRATIVE” RECONSIDERED: AN ANALYSIS OF THE NARRATIVES OF FIBROMYALGIA PATIENTS WHO “DO NOT ACCEPT” THEIR ILLNESS**

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## **Abstract**

“The quest narrative,” one of three types of illness narratives defined by A.W. Frank, is proposed as an ideal type. It requires the “acceptance” of illness and the ill person’s belief that something new is to be gained through the experience. This moral narrative, as a “successful living narrative,” may devalue the narrative by people who do not accept illness as a failed way of living. It is difficult to see how people around an ill person and socioeconomic factors influence the process of accepting suffering and telling his/her experience, because individual efforts of the moral agents are emphasized.

The purpose of this study is to reconsider “acceptance” of illness as a requirement for “the quest narrative.” In this paper, I use the narratives of fibromyalgia patients who do not accept their illness. Through analysis of the narratives, I mainly obtain the following four insights. First, not only the ill person but also people around him/her could share the responsibility for the “acceptance” of their illness. Second, telling and listening to a “feel-good story” could make one a normal ill person. Third, if people around the ill person do not accept his/her illness, the responsibility of “acceptance” of illness could be individualized. Finally, even if the ill person does not accept his/her illness, he/she could tell his/her story to share his/her experience with others.

These results suggest that “the quest narrative” should allow a variety of ways of “acceptance” of illness such as sharing or collaborating on it with others. Against the danger of listening to only “the feel-good story,” *the listener* has to find the various “quest” in each illness narrative, and “the quest narratives” with rich variation should be brought up.

Key words: illness narrative, quest narrative, “acceptance” of illness

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## 1. Introduction

### *1.1. The “quest narrative” as the “ideal type” of illness narrative*

Illness narratives refer to the “the story-telling and accounting practices that occur in the face of illness” by those who are sick and those around them (Bury and Monaghan 2013: 81). Illness narratives have been the subject of active discussion since the 1980s. The concept was primarily developed by G. Williams, A. Kleinman, M. Bury, and A.W. Frank and continues to be a topic of interest for many researchers. The three types of illness narratives identified by Frank (Frank 1995) have had a great influence on subsequent studies as a template for illness narrative analyses: the “restitution narrative,” the “chaos narrative,” and the “quest narrative.” The “restitution narrative” has a plot of restoring health, and is seen in “particularly those who are recently ill and least often the chronically ill” (Frank 1995: 77). The “chaos narrative” is an unordered narrative created in the midst of suffering and is told by a confused ill person who cannot see the path forward. Lastly, the “quest narrative” uses the “hero’s journey” as its motif, and accordingly incorporates its scheme of departure, initiation, and return (as described by American mythologist J. Campbell). Thus, the quest narrative becomes a story of how the sick person himself tries to stand up to his suffering. Although “actual tellings combine all three,” and as such cannot be categorized in such a simple manner, Frank presents these typologies with the intention to listen to the sick and think with their stories (Frank 1995: 23-5). However, Frank values the quest narrative more highly than the other narratives because the experience of illness has been dwarfed by medical narratives.

Since the establishment of modern medicine with the advent of biomedicine at the close of the 19th century, disease has been regarded as something that exists inside the body and that only specialists can understand. In addition, advances in medical technology have encouraged doctors to focus on numerical values and images rather than subjective explanations of sickness, and “disease” rather than “illness” has been positioned as the target of treatment. As such, sick people are obliged to devote themselves to the medical treatment under the control of doctors and become responsible for their recoveries.

In modern society, the “restitution narrative,” which is influenced by an institutional story that values health and asserts that the body is repairable, is disseminated as a master narrative<sup>1)</sup>; the illness-related suffering of individuals is not authoritatively recognized and the meaning of “illness” is not sought. However, in an age in which people live with chronic illnesses that cannot always be cured and in which medical science does not always achieve the victory over suffering that it promises, ill people must represent themselves and take responsibility for their own illnesses (Frank 1995: 13). Frank believes that it is achieved by the “quest narrative” with the ethics inherent in postmodern where ill people are “trying to make

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1) Frank’s master narrative is based on G. Spivak’s argument (Spivak 1990), which can be simply described as “a story told in the dominant culture of the whole society” (Sakurai 2005: 178).

moral sense of their own suffering and who are witnesses to sufferings that go beyond their own” (Frank 1995: 19). “Witnessing of suffering” entails “one duty to the commonsensical and to others” (Frank 1995: 17), but also rebuilding the moral subject to fulfill it<sup>2)</sup>. In this regard, Frank presents the “quest narrative” as an “ideal type” of illness narrative.

### *1.2. Problems inherent in the “quest narrative”*

As mentioned above, Frank’s three narrative types have had a major influence on subsequent studies, and numerous studies have been conducted to analyze illness narratives. At the same time, however, this approach has garnered various questions and criticisms, most of which have been related to the “quest narrative.” For example, P. Atkinson, who raised the harshest criticisms of Frank, said, “(in Frank’s account) narratives are celebrated insofar as they construct the active heroism of the ill person,” and accuses Frank of not treating all the narratives equally because he prioritizes ethics over analysis (Atkinson 1997: 338). Meanwhile, M. Bury, a leading researcher in the area of illness narratives, stated, “the actual relationships in which the individual is embedded may be lost in an overemphasis on positive ‘personal narratives’ that are uncritically reproduced by the sociological author,” pointing out the possibility that this emphasis on the ethics of the narrative (becoming a “witness” of the narrative) underscores the consideration of actual social relationships (Bury 2001: 277). In addition, Bury describes the serious problem of moral narratives, such as the “quest narrative,” as follows:

By developing a narrative of ‘successful living’ in the face of illness, or by suggesting that reflexive and ‘meaningful’ deliberations on experience have been achieved, the individual may, of course, be self praising or implying criticism of those that fail. (Bury 2001: 277)

Whilst Frank is aware of these problems<sup>3)</sup>, Bury is more cautious about them, because in the same way that the “restitution narrative” suppresses the voices of the ill, the “quest narrative” may undervalue some narratives, if they are not comport with it, which might be regarded as failed livings of illness experiences.

These criticisms of the “quest narrative” have clarified the ethics and their detractors underlying Frank’s argument, and most have come from a methodological or theoretical perspective. However, as Frank states, “I now prefer the idea that this theory awaits further living and the stories of those lives” (Frank 1995: xxi), he wants us to evaluate and

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2) “The quest narrative recognizes ill people as responsible moral agents whose primary action is witness; its stories are necessary to restore the moral agency that other stories sacrifice” (Frank 1995: 134).

3) Frank notes that the quest narrative risks becoming a phoenix narrative. The “antidote” to these narrators’ beliefs is the “chaos narrative,” which reminds us that illness can be difficult. In addition, leaning more towards a narcissistic narrative can benefit from a “restitution narrative,” which reminds us that rational people are more likely to recover their health and need help from others to stay healthy (Frank 1995: 134-5).

develop this theory empirically. Therefore, this study aims to critically recapture the “quest narrative” using the narratives of patients with fibromyalgia (FM). Additionally, this study places particular focus on narratives in which patients “do not accept” their illness<sup>4)</sup>. Before beginning this examination in earnest, the following section will provide an explanation of the background for this focus on “do not accept” narratives with respect to illness.

## 2. “Acceptance” of Illness

### 2.1. “Acceptance” of illness as a requirement to establish a “quest narrative”

Although the “quest narrative” is often understood in terms of the “hero’s journey” scheme, Frank also discusses the requirements for the formation of such a narrative:

Quest stories meet suffering head on; they accept illness and seek to *use* it. Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person’s belief that something is to be gained through the experience. (Frank 1995: 115)

In addition, the requirements for establishing a “quest narrative” that can be confirmed include the ill person’s attitude of “accepting illness and trying to use it” and their belief that something can be gained through their experience:

The quest story accepts illness as a calling, a vocation. This vocation includes responsibility for testimony. (Frank 1995: 166)

The quest narrative recognizes that the old intactness must be stripped away to prepare for something new. Quest stories reflect a confidence in what is waiting to emerge from suffering. (Frank 1995: 171)

Based on these descriptions, it is clear that narrators must accept their illness and believe that they gain something new from their suffering when forming a “quest narrative.” It is thus necessary for the narrator of the “quest narrative” to accept their illness as a calling and be aware of the importance of what they have gained, rather than being fixated on what they have lost due to illness. On the contrary, when trying to regain what was lost through their suffering

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4) In sociology of medicine, “illness” is something experienced by both patients and their families, “disease” is something defined and targeted by medical practitioners, and “sickness” is represented in terms of social parameters, and these terms can be considered separately. Based on this classification, although the terms “illness/disease/sickness” must be used carefully, in the patient’s narrative, each may be described in an ambiguously overlapping manner. Frank also states that “the illness experience is an experience in and of a diseased body” and highlights the inseparability of “disease” and “illness” (Frank 1995: 223). Therefore, this paper will proceed with its discussion on the assumption that the terms “illness/disease/acceptance of sickness” will overlap.

(e.g. one's health and livelihood), narrators may not accept their illness and their stories may either be insufficient to form a "quest narrative" or come to be understood as a different form of narrative.

## 2.2. *Can narrators who "do not accept" their illness be moral agents?*

While Frank argues that ill people can assume an attitude of accepting their illness and the belief that suffering will bring something new to them by virtue of that illness, just as with the quest narrative, there has been debate over how these patients could behave and live. For example, T. Ito states that even though in Frank's description the narrators of quest narratives do not necessarily achieve "complete transformation," but such subjects are implicitly expected to engage in endless efforts in self-reflection and self-narrative transformation. As such, he points that the experience diverging from the "quest narrative" would be interpreted as, "In the end, the ill people should be overcome by recreating their own story" (Ito 2010: 57). J. Amada also suggests that these narrators are paradoxically required to become 'model students' for medical treatment" who are "heroes as Bodhisattva"; they "accept the 'impermanence of their own bodies' and are 'modest and thoughtful heroes' who desire themselves in relation to others and reimagine themselves" (Amada 2008: 617).

The emphasis on individuals' efforts to become moral agents and the lack of consideration of societies that desire such individuals make it difficult to consider the presence of others' involvement and socio-economic factors in the process of accepting suffering and ascending to the level of "heroes as Bodhisattva." Moreover, as the point of focus becomes the narrator's moral transformation, the narrator's motives and context of the narrative are not sufficiently examined, and the way of living or being of illness people may be evaluated in terms of distance from the "hero as Bodhisattva" archetype.

Among these issues enmeshed within the images of illness presented by the "quest narrative," this paper engages in particular critical discussion about the "acceptance" of one's illness as a prerequisite for the establishment of a "quest narrative" by FM patients who "do not accept" their illness. This discussion will attempt to consider, while accounting for individual circumstances and human relationships, whether the narrators of narratives indicating a refusal to "accept" their illness, as has not been recognized as a "quest narrative" in Frank's view, may ultimately fail to become moral agents.

## 3. Methodology

### 3.1. *Fibromyalgia*

FM is a disease<sup>5)</sup> characterized by systemic chronic pain as a primary symptom in addition

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5) FM is considered to be one of a group of "contested illnesses." "These are illnesses where sufferers claim to have a specific disease that many physicians do not recognize or acknowledge as distinctly medical" (Conrad and Barker 2010: S70). While it can be argued that such illnesses are not yet referred to as "diseases" at this stage, this paper opts to respect the experience of the patients concerned and describes FM as a "disease."

to various secondary symptoms. Although there are individual differences in the type and degree of symptoms, patients report experiencing constant and unbearable severe pain in many cases. FM is believed to occur more frequently in women than men, and predominantly in middle-aged women or older. The causal mechanism of FM is currently unknown, and no cure has been established to date, forcing patients to endure long-term suffering. Although FM is a disease that makes working difficult and substantially interferes with patients' daily activities, under the current system, it does not meet the requirements for designation as an intractable disease (*shitei nambyo*), and it is difficult for patients to receive a disability certificate. As a result, many patients are in very difficult situations physically and financially.

### 3.2. Data collection

We conducted semi-structured interviews with 16 FM patients from December 2013 to February 2015 through patient associations and individual patient referrals. The time allotted for each interview was approximately 1-4 hours. Before starting the interview, patients were briefed regarding the study purpose, study details, methods, handling and protection of personal information, publication of study results, and other items, and the informed written consent of each patient was obtained. Interview questions concerned patients' overall experience with FM, but we listened generally to the patient's descriptions of their symptoms and life problems from disease onset to the date of the interview. This study was conducted with the approval of the Research Ethics Committee, Departments of Sociology and Anthropology, Graduate School of Human Sciences, Osaka University.

This paper focuses on the narratives relevant to subjects such as "accepting/not accepting illness,"<sup>6)</sup> and discusses an analysis centering on the individual context. Of the sixteen participants, seven used the phrase "accept/do not accept" with respect to their illness and made specific mentions of this aspect of their perspective. Among them, at the time of the interview, five participants expressed that they "accept" their illness, and two participants indicated that they "do not accept" their illness<sup>7)</sup>. The five participants who stated they "accept" their illness did not account for a large proportion of their total narratives. However, the topics related to "not accepting illness" by two participants accounted for a considerable proportion of their total narratives. In light of this, this paper will focus on the narratives of two participants who "do not accept" their illness, which was abundantly talked about the topic of

6) In this paper, only the narratives using the expressions "accept illness/do not accept illness" were analyzed. Of course, these narratives can also be established without the specific phrases "accept illness/do not accept illness," and can sometimes be expressed in other ways. A limitation of this research analyzing only the narratives that have direct expressions, is considered to be the limitations of the method of analyzing what was spoken as well as the limits of the author's abilities. An analysis of "what was not expressed but was spoken" and "what was not spoken but was attempted to be told" are topics for future studies.

7) To date, I have conducted follow-up interviews with several people, one of whom stated that she had "accepted" her illness during the first interview, but in a follow-up interview conducted one year later, she indicated that there were aspects she was now finding difficult to accept. Although a more detailed analysis will require a separate manuscript, it must be recognized that narratives can shift due to the influence of various factors such as the passage of time.

“acceptance” of illness<sup>8)</sup>.

#### 4. Narratives of Fibromyalgia Patients Who “Do Not Accept” Their Illness

##### 4.1. *“I’m still fighting, so I do not yet have an answer”*: Ms. A’s narrative

Ms. A (female/40s, interview conducted in 2014) has spent most of her life in pain. Since she was a child, Ms. A said, “I’ve been all over the place [clinics and hospitals]. I’ve been to so many places that I can’t remember.” She was diagnosed with FM only three years before the interview. During the period before she was diagnosed, Ms. A suffered from pain almost constantly, but said, “I can’t help it. I just gave up. My life has been overwhelmed with pain, I believed there was nothing that could be done,” and she spent every day enduring the pain. A few years ago, after taking a drug believed to be effective in treating FM, she was able to manage her pain considerably. However, even now, the pain persists, and she always feels some degree of dull pain except when she is sleeping. The symptoms of FM are accompanied not only by pain but also various secondary symptoms such as a feeling fatigued and a decline in cognitive capacity, and when she is under physical or mental burdens, these symptoms become exacerbated. As such, Ms. A is always worried about whether her body can endure various everyday situations.

For Ms. A, FM is the one which has continued to prevent another life that would have been possible and set of experiences would have been possible without it. She does not think of FM as bringing her any positive experiences, though it surely brings suffering.

Author: I think there are probably many difficult things in life. Hmm, what should I say?

Well, I wonder how big it [FM] is (in your life).

A: I wonder (laughs). It must be the biggest thing of setbacks.

Author: Setback.

A: I think it’s very bad to lose one’s health because I’m not a mature person. I don’t think there is any positive side to it. There is only a negative image.

Author: Well, have you obtained any positive thing from getting sick...?

A: Positive things...good things...?

Author: Somehow, the person who got sick...

8) I explain briefly about the process by which the narratives “not accepting” the illness were generated. In the case of Ms. A, the topic was expressed in the flow of talking about illness experience. Ms. A’s narrative, which describes FM as the greatest “setback” of her life and repeatedly refers to loss of self-confidence and a possible “healthy” life, is an indication that she found the illness to be unacceptable. By contrast, with Ms. B, a word from the author had a substantial influence on the generation of her narrative. Ms. B, who is convinced that FM is not a curable disease and who has learned her own way of living with her illness, seemed to “accept” her illness. The author then asked, “Do you accept your illness for now,” and Ms. B replied, “I want to ask what it means to accept illness.” During the interview, the author’s question, which was almost oblivious to the violence inherent in the expression “accept” with regard to illness, inspired Ms. B to accusatorily inquire as to the violence of the question, leading to the generation of a “not accepting illness” narrative.



A: Oh, yes. Some people say (that there was) a good thing (about getting sick).

Author: Yes, sometimes.

A: I wonder how they can say so. Right now, I'm not at a stage where I think there is a good thing (about getting sick). I might understand it before I die (laughs). Wow, hmm. I'm still fighting, so I don't have an answer yet. But I don't think it's a good state now. Well, maybe I expect too much. If I wasn't sick, it would have been different, and my life would be bigger. Yes. I If I was fine—it might sound strange the assumption if I was fine. I have a ton of things I want to do, and I think it might have been possible if I wasn't in pain. When I think so, I'm very disappointed.

The phrase “if I wasn't sick” and “if I was fine” that often appear in Ms. A's narratives clearly express her disappointment that FM has prevented her from doing things which she really wanted, and show hope for improving her life without giving up. However, Ms. A is worried about whether she can continue fighting in this way.

Author: You didn't intend to (get sick).....

A: Of course, That's why it's hard. Even though there is nothing else I can do anymore, my husband doesn't understand. So, I say “you don't understand yet” and blame him. Well, I don't like myself saying that. And, I have tried to do so many things, all kinds of things, such as moxibustion and acupuncture. Even now, I'm still looking for various options that would be effective. I wonder if this will last forever. I have a strong desire to make my current condition even a little better. But I wonder if I should accept the illness and stop looking for hospitals anymore. I'm not sure about that. I wonder how I will consider all of this. This is worrisome for me.

The endless quest for ways to “make the condition even a little better” complicates the way Ms. A faces her illness. She knows it is not good to overwork herself, but financial circumstances are also involved in the difficulty of receiving treatment in order to maintain the status quo. Ms. A works part-time, but feels a physical and mental burden from FM. However, as the income she earns from this work is used for her medical expenses, she cannot just quit. Against this background, Ms. A's explains, “I live a life that I am always worried about my body.” That being said, Ms. A does not think only about her body:

A: I think that I should not forget about it [her illness experience]. I want you to learn more about this disease, and I hope that more people will do so. I want to do something like that. I don't really know what to do or how to do it. Maybe if I had a bit more time? If I had the confidence.

Ms. A is frustrated by not only the general public but also medical staff have little knowledge of FM, and dissatisfies with the fact that patients are not properly treated medically and socially, therefore she wants to be involved in some activity to raise awareness of FM. Although she currently cannot afford to do so physically or mentally in any concrete manner, Ms. A is living her daily life, hoping to do such activities someday.

#### 4.2. *“What else do you want me to accept?”: Ms. B’s narrative*

Ms. B (female/50s, interview conducted in 2014), who is considered to have the most severe state of FM, has been spending her days at home while receiving welfare services since she first became aware of her condition ten years ago. Ms. B became hypersensitive due to disruption of her autonomic nervous system, and is suffering from various “unidentified complaints” in addition to pain. For such symptoms, Ms. B has decided that she will only do what is covered by public insurance. As Ms. B is a former nursing teacher, she believes that several treatments that are not covered by public insurance and are not supported by evidence exist to generate revenue by exploiting patients’ desires to be cured. Therefore, Ms. B has no intention to use treatments that have not been “confirmed to be effective.”

B: I don’t use such drugs. Yes. Even if you use such medicine, this illness will never be cured. I will use what can be covered (by public health insurance). If that doesn’t help, then there is no way. I don’t think it will ever be cured. To be clear, this is an intractable disease. There is no cure.

Despite being convinced that FM is an incurable disease, Ms. B has never accepted her illness. From the beginning, Ms. B was skeptical about the notion of “accepting/not accepting” illness, and is deeply upset by people who say she “does not accept” her illness.

B: (I want to ask you), what does it mean to accept one’s illness? I’m often told this. My doctor said to me, “You haven’t accepted your illness yet.” What does it mean to accept my illness? I’m already sick. How else can I accept the illness? This is such a disgusting word. I mean, whether I accept my illness or not, I’m living with illness naturally because I am sick. What else do you want me to accept? Well, you don’t want me to complain about my illness. Maybe you don’t want me to be selfish. That is what it is. You may say, “You should have more fun.” But we can say that we are alive because we are facing forward, right? How can I face forward anymore? I have no idea how I can convince others that I am just turning to the front. People say such awful things to sick people. They are asking me to do something I can’t. I think it is enough just to live my life. I think I am already looking ahead.

It seems to Ms. B that the people around her want the sick to not complain or be selfish, as suggested by the phrase “accept your illness.” Ms. B, who is repelled by this pressure placed upon her by those around her, and states that it is not the patient who “does not accept their illness,” but rather the healthy people around the patient.

B: Healthy people can’t cope with the illness, after all. They can’t accept the illness. They can’t accept there is such a sick person in their family. They cannot accept the illness. They would say, “Why did my wife develop this illness?” or “Why did my kid have this illness?” After all, if they think so, the sick people themselves cannot accept that. People around the sick blame it on the patient. That’s why, they say “Can’t you live a little more fun?” or something like that. It’s totally misguided.

The question of whether or not to accept the illness, which could be shared, is imposed only on the sick person. And the people around them want the ill person to show that they are “fun” to live. Regarding this point, Ms. B states that the people around the sick only want to hear “feel-good” stories.

B: I don’t know how people around want the sick people to live. But, for example, an article about a sick person tends to be the one that makes readers feel good. The same is true of TV. The same applies to movies. But I think these do not capture the real experience or feelings ill people have. I often think that is very superficial. There were probably many times when they were suffering. Ignoring it, only the good-feeling parts are taken up (in the media). Perhaps (the media is) telling everyone to live that way. Only that kind of (feeling good) part is expressed. Looking at it, people evaluate that the sick person is doing his/her best or living positively. Well, if I don’t live like that way, then are you saying that I’m not living positively?

Here, Ms. B’s “the one that makes readers feel good” refers to the stories of sick people who have overcome their illness or who remain positive even while living with their illness, and who invite the tears of those who see and listen. People evaluate such stories as indicating that those telling them are “doing their best” or are “living positively,” but from Ms. B’s perspective, such narratives exclude the aspects that show that the sick people are suffering more than they express. These are pleasant, feel-good stories for healthy people. Stated differently, Ms. B believes that “accepting illness” is the attitude that healthy people expect sick people to have, but is far from the attitude that Ms. B can take in reality. However, this does not mean that Ms. B is not living in a positive way.

B: Why am I the only one with such a disease? I’m very angry. Yes. I’m angry, so I won’t

say that I “accept” my illness as everyone would say. I think that when I “accept” it is when I die. When that time comes, I don’t have to live anymore. That’s why I don’t have to accept it. Right? I’m thinking that way. I think that’s what it means to live. That’s why I’m looking ahead. People just live their lives. Therefore, there is no right for others to instruct the sick person, whether to accept the illness, to look forward, or to speak bright words. Whatever we say should be taken as it is. I think that people around us should listen.

For Ms. B, being alive is nothing more or less than facing forward. One of the ways she takes responsibility for her illness is not to terminate her life that cannot be turned back but to live it, despite the internal conflict that “I am the only one who has such a disease.” However, such an attitude is not what of the sick person that people around want. Ms. B wants the people around the sick to hear their voice instead of imposing a desired image of the sick person on them.

## 5. Discussion

### *5.1. Affirmation of one’s life through rejection of responsibility and “acceptance” of illness*

This section will examine the way of living of the sick person based on the narratives of FM patients who “do not accept” their illness, as presented in the previous section.

First, although Ms. B’s narrative contains a number of claims, the following two are particularly important: (1) it is not the patients who do not accept the illness, but the people around them; and (2) the sick people are living with their illness regardless of being “accept/not accept” their illness. At first glance, these claims resemble a “chaos narrative” and impose responsibility for one’s illness on others. However, if “illness” is different from “disease” and is experienced through interactions with one’s surroundings<sup>9)</sup>, it should not be sufficient for an ill person to unilaterally assume an attitude of accepting or not accepting the illness. When Ms. B stated, “Whether I accept my illness or not, I’m living with illness naturally because I am sick,” the illness is precisely a “disease,” and as it is something that exists within her body, it is something that only she experiences. By contrast, “living with illness” is the very experience of “illness,” which can be lived through interactions with others. It is for this reason that Ms. B demands the attitude of “accepting” the illness from the people around her who experience illness. As discussed by Kleinman and Frank, “illness” refers to a wide-ranging set of experiences that does not stop with the ill individual. In other words,

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9) “Illness” is recognized as being experienced by patients and their families, but it may be confirmed once again that it is more than it is in practice and by definition. To define, Kleinman stated, “Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability” (Kleinman 1988: 3), while Frank is more concise, describing illness as the “social experience of that disease” (Frank 1995: 223).

the responsibility of living with an illness could be shared with the people around, rather than solely with the sick.

Incidentally, Ms. B takes on living with an illness paradoxically by taking the attitude of not accepting the illness, while she has a critical look at her surroundings. Suffering such as the unbearable pain, stiffness, malaise, and hypersensitivity that plagues Ms. B is the very life in which she lives. Thus, in Ms. B's case, denying this suffering is in essence a rejection of her life itself. The negative attitude of not accepting her illness as such is paradoxically a source of her empowerment to affirm her own life and take on living with the illness.

## 5.2. *"Feel-good" stories and normalization of the image of the ill person*

Ms. B, who takes on living with the illness by "not accepting it", is confused because this is not the attitude desired by others. While saying, "I don't know how the people around me want me to live," Ms. B is clear about how other people want sick people to live their lives. People want a "feel-good" way of life that is likely to be picked up by the media as an uplifting side story, such as "I have suffered from illness and it is still difficult, but I am doing my best!" Of course, Ms. B knows that it is not a virtual image in the media, and that there are actually people who live this way, and she admires such people. However, Ms. B also says that such people are "enlightened people."

B: After all, I think that people have their own way of life. I think that if you manage your mind well, you can live barely. Well, I think some people will feel good if they intend to deal with this illness well, and then they may accept that this pain is inevitable. But like me, there are other people who think not only "Why do I get sick like this?," "I was supposed to be doing well and working," but also try to keep the range that they can move even a little. It doesn't matter if there are such people, right? And, I think that an "enlightened person" is someone who is a kind of great saint. People like that can say good words. I think that people who say feeling-good things that make people feel good are amazing. I am the type of person who can't say those kinds of things at all. That's probably why TV stations turn their noses up and newspaper journalists turn the other way. Because I just say negative things. The things I say aren't feeling-good and comfortable, you see.

When Ms. B says, "intend(ing) to deal with this illness well", it seems to mean accepting the illness. And she says that people who accept their illness are "enlightened people." The "feeling-good things" by the "enlightened person" can be overlapped on Frank's "quest narrative." Frank portrays the narrator of the "quest" as a "hero" who "discovers alternative ways to experience suffering" (Frank 1995: 119). The model of that "hero" is not "some Hercules wrestling and slugging his way through opponents, but the Bodhisattva, the

compassionate being who vows to return to earth to share her enlightenment with others” (Frank 1995: 119). A Bodhisattva is a person who seeks enlightenment, but has not yet fully achieved it, and Ms. B’s “enlightened person” and Frank’s “Bodhisattva figure” can both be said to suggest those who are positioned near “enlightenment.” However, Ms. B feels anger rather than acceptance of those people’s words, as envisioned by Frank’s “quest narrative.” It is important to note here that Ms. B is frustrated not by the ill people who are picked up by the media, but with the way the media affords attention and people’s expectations regarding those who are ill. Despite saying “why did I get this illness” repeatedly, not accepting her illness and not saying things that “make people feel good”, Ms. B faces her illness in her own way and struggles every day. Her way of life is, however, far from the image of an ill person that is expected by society. As such, from Ms. B’s point of view, the image of the ill person, which is disseminated by the media and has come to be expected by people around ill person, is regarded as defining the way of life of ill people, and pressuring them to adhere to it while marginalizing other way of life.

### *5.3. Individualization of the “acceptance” of illness*

Ms. B’s narrative asserting that the people around the ill person, rather than the patient, are unable to accept the illness suggests that the shared responsibility for an illness is imposed only on the ill person. In other words, it could be said that this is a situation in which the “acceptance” of illness is individualized. As mentioned above, from the viewpoint of “illness,” the “accept/do not accept” state is a result or the process of the interaction between the ill person and the people around them. Therefore, it is achieved not only by the individual efforts of the ill person. However, if the people around a patient do not accept the illness, that patient must shoulder their burden alone. This type of situation is found to have arisen for Ms. A as seen in section 4.1. Ms. A’s husband does not understand her illness, no matter how many times Ms. A explains it, and he complains every time she goes to visit the hospital:

Author: Does your husband say anything about your going to many hospitals?

A: Hmm, it’s like “You go again?” Yeah. Because we still have only one car. Well, when my husband goes to work, I ask him, “I’m going to the hospital today, lend me the car.” Then, especially on a rainy day, he makes a reluctant answer. He also says things like, “You’re going again? You didn’t?” and “You won’t get any better even if you go.” In fact, my disease is not curable (as I have told him many times). Anyway, he still complains with a really unpleasant look on his face. I don’t know whether it’s hard for him to accept or if he just doesn’t want to understand.

In addition, not only her husband but also, Ms. A’s child does not actively offer to help her. Regarding the reason for this, Ms. A says, “Well, I wonder, because it [the illness] is not hers.”

Ms. A has a feeling of “giving up” on her husband and child in this respect.

A: What can I say? Maybe I’m giving up. Yeah. Um, if I laid down, he wouldn’t do anything for me. I already know that he is that kind of person. I’m pretty much giving up (what I expect from him). I know that is not good.

Since it is unlikely that her family will “accept” her illness, Ms. A performs the household chores and suffers with her illness alone, no matter how difficult it is. Ms. A’s case suggests that the “acceptance” of illness becomes individualized when those around the sick person do not accept the illness and he/she stops expecting anything from those around his/her.

#### *5.4. Towards the sharing of experiences*

As we saw in 4.1, Ms. A, who has a desire to improve her condition even a little, is concerned primarily with her own body, but also wants to be involved in activities for raising awareness of this disease. This is because she wants to do something about the incomprehensibility of her surroundings about this disease as well as the current reality that the majority of people are unfamiliar with and unaware of FM. Ms. A states “there are few people who have a deep understanding of FM,” and one day when she complained at a hospital that “it hurts here,” she was told “everyone feels pain there when they move” by a nurse. She says “that remark really made me mad.” As pain is invisible, the extent of one’s pain cannot be measured objectively. In addition, the pain of FM patients tends to be belittled because healthy people generally imagine pain only to the extent that they have experienced it. This invisibility of pain gives room to regard FM as malingering or somatoform disorder, and many patients become mentally trapped without understanding the people around them. In response, Ms. B has established a patient advocacy group and participates in consultations with patients.

Author: What kind of things do you talk about with the patients?

B: In short, there are many consultations that there is no one who understands this condition. It means that even the family does not understand. They [people calling and asking for her advice] say they are told by their family that “You say you’re in pain or it hurts, but you’re always on your smartphone.” [...] Their family say that they are lazy or they are not sick after all. So, they tell me that no one doesn’t understand them, and reveal their situation to me. Then I say things like, “yeah, yeah,” and “right, it’s true at times like this.” By indicating assent, they may feel at ease. Some people (in severe situations) ask their husband to talk to me on the phone and try to make him understand their condition. After all, they call me because it is hard for them when their family does not understand their condition.

As mentioned above, Ms. B, who joins consultations for patients with the same disease and who suffer from the incomprehension of people around them, is placed in a severe category among FM patients. Why does Ms. B engage in such activities, even though her symptoms are exacerbated by telephone consultations and public activities?

B: Maybe it's hard to be alone without doing anything. [...] I am sick, I have my own knowledge, and I understand myself to some extent. When I believe that there were many people like this [people with the same illness] around me, I think this [my experience] might be useful.

Ms. B, who did not keep her experience of suffering to herself and tries to put it to use for others, does not “overcome” her suffering. However, Ms. B’s act of listening to the voices of others who are suffering and talking about her experience can be superimposed on Frank’s notion of “testimony.” Both Ms. A, who desires to be involved in awareness-raising activities, and Ms. B, who is actually engaged in such activities, “do not accept” their illness. However, towards the sharing experience with ill patients, medical personnel and the general public, Ms. A is looking forward to delivering her narrative, and Ms. B is delivering her narrative.

## 6. Conclusion

This paper examined the circumstances of ill people who do not “accept” their illness based on the narratives of two FM patients, and obtained the following insights: (1) responsibility for “accepting/not accepting” one’s illness can be shared with those around you beyond just sick people; (2) the image of the ill person has become normalized through the sharing of “feel-good” stories, and the way of living or being of sick people who deviate from these can be excluded; (3) “acceptance” of one’s illness can be individualized if the people around them do not accept the illness; and (4) even if one does not accept his/her illness, sick people can tell their narrative toward sharing their experiences with others. Based on these findings, this section proposes the need to acknowledge the various ways of “acceptance” of illness and the diverse forms of being of the sick person as a moral agent towards the new development of the “quest narrative.” This paper concludes by mentioning that the “quest narrative” can be a master narrative.

For Frank, “acceptance” of illness as a requirement for the formation of the “quest narrative” entails the patient’s acceptance of their illness as a calling. However, the narratives examined in this study show that this mindset can be shared with the people around the ill person. Of course, Frank depicts the process of overcoming suffering in a heroic fashion because “the quest of finding meaning in suffering can only be undertaken oneself” (Frank 1995: 180). It must be kept in mind that sharing such a narrative is not easy because the



experience of suffering can only be presented to others in a “half opening” manner. However, it would be practically impossible to become a “hero” without the involvement of others. Frank is no exceptions to this; he wrote that he had survived thanks to the care of his wife, who accepted and supported him about his heart attack and cancer experience (Frank 1991). The existence of such positive or negative others is greatly involved in the “acceptance” of illness. It is important to clarify how ill people can express that they “accept/do not accept” their illness, and to discover what/who can make such an attitude possible, as this can open numerous possibilities for the manifestation of such “acceptance.” By doing so, it may be possible to perceive, encounter and present a unique “quest” for each patient.

In addition, in the narratives of Ms. A and Ms. B, their illnesses are not accepted, and there are many negative episodes such as accusations against people around them and self-denial. However, they face their illnesses in their ways and indicate their willingness to make use of their illness experiences. These narrators may be different from the moral agents that Frank presupposes, but in the consideration of a moral relationship arises in the process of the collaborative work between the narrator and the listener, whether or not a narrator becomes a moral agent would depend largely on the other person who listens to the narrative. The ways of living and being of the ill person “not accepting” their illness observed in the narratives provided by Ms. A and Ms. B challenge our expectations regarding ill people and offer us a new moral relationship. Whether such “not feel-good story” will be interpreted as a “quest narrative” may depend on the ethical responsibility of the listener who assigns values to the stories of others.

Finally, regarding the valuation of stories by others, I would like to mention the situation in which the “quest narrative” can be a master narrative. As mentioned in the introduction, Frank presents the “quest narrative” as a counterargument to the assertion that the “restitution narrative” is circulated as a master narrative and that ill people have been deprived of a voice. It is believed that the narrators of “restitution narrative” only imitate the stories brought by medical personnel and the media and cannot describe illness in their own words. However, the consumption and imitation of stories occurs not only with the restitution narrative but also with the quest narrative. A variety of stories are told by ill people themselves on the Internet, and at patient’s groups, people who have survived their suffering and transformed into a “communicative body” (Frank 1995: 48-50) tell their stories to people in the midst of illness who seek salvation. This is a model story<sup>10)</sup> of patient communities in which ill people confirm their position, admire it, and imitate role models.

However, as a model story, the “quest narrative” is also a narrative that is easy for the media

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10) Of the individual life story, A. Sakurai calls the one borrowed and referred to within the community as a “model story.” “Model stories could be oppressive and restrictive with respect to the generation of new and different narratives, because they are told as if they were having authority, telling the truth, and having a clear framework within their community” (Sakurai 2005: 180).

to pick up as a dramatic tale. Additionally, the “quest narrative” may actually be more useful to medical practitioners and the general public rather than the sick. Because highly developed modern medicine, however, reminds us that there are numerous illnesses that remain unable to be cured. In such a situation, “recovery narrative” seems to be more inappropriate to society than the sick, as it can give a sense of futile hope and excessive fixation on healing. By contrast, the “quest narrative” is a rational narrative that does not place costs on society, because the *humanist* solution to face one’s suffering and to accept illness is attempted on a personal level without actually being cured. That is, the “quest narrative” is also subject to the influence of institutional stories that reflect the expectations of others, such as economic rationality and the desire for catharsis. Therefore, the “quest narrative” is implicitly and explicitly given the status of a master narrative by those who consume it or attempt to use it, giving rise to the risk that only the voices of ill people who conform to society’s preferences are recognized and heard.

To deal with the danger that only such “feel-good” stories will be demanded and consumed, it is necessary to recognize the various ways of life and increase the variety of narratives, as Frank intended. However, the ethical responsibility of the listener, which has been largely neglected until now, will be called more than that of the narrator. Its responsibility should be fulfilled by recapturing the various narratives we have heard or have not heard properly, not to mention the story to be told henceforth, as well as presenting a new version of the quest narrative.

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